

# THE PENNSYLVANIA DEPARTMENT OF AGING



SEPTEMBER 24, 2014

1<sup>ST</sup> ANNUAL ALZHEIMER'S DISEASE  
AND RELATED DISORDERS FORUM

SUMMARY

**1<sup>st</sup> Annual Pennsylvania Alzheimer’s Disease and Related Disorder Forum**

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## **I. Executive Summary**

On February 7, 2014, the Pennsylvania Alzheimer's Disease Planning Committee (Committee), established by Governor Tom Corbett, through Executive Order, and chaired by Secretary of Aging Brian M. Duke, presented the *Pennsylvania State Plan for Alzheimer's Disease and Related Disorders* (Plan) to the Governor.

The Plan,<sup>1</sup> presented to the Governor, contained seven (7) recommendations for responding to the current Alzheimer's Disease and Related Disorders (ADRD) crisis in the Commonwealth, and its anticipated growth in future years. Pennsylvania has the fourth highest percentage of adults aged 60 and over in the nation. The incidence of ADRD is directly related to age; thus, over 400,000 Pennsylvanians currently live with ADRD, and their families (one in twelve), friends, and communities are directly affected.

The planning process began in June of 2013, with 6 public hearings and monthly meetings of the 26 committee members. The committee members included care providers, elected officials, academic researchers, caregivers, and a person living with ADRD. The committee developed recommendations that included, enhancing public awareness, promoting brain health, providing an continuum of ethical care, supporting family and non-professional caregivers and those living with ADRD, building a competent workforce and educating providers and fostering of research, while remaining mindful of limitations on resources.

The Governor formally accepted the Plan on June 12, 2014, directing the Department of Aging to hold the first annual State Plan for Alzheimer's Disease and Related Disorders Forum.

### **The Forum**

Within Recommendation 1 of the Plan a goal was established by the Committee to hold an annual summit or forum in order to evaluate progress of the Plan, strengthen partnerships, build community support for the Plan, recognize excellence and identify next steps. The inaugural forum took place on September 24, 2014 in Harrisburg, Pennsylvania.

The Forum brought together over 150 participants, including government officials, Alzheimer's Association chapters, other advocacy groups, and leading academic researchers. The keynote speaker was Dr. Randi Chapman, Director of State Affairs for the National Alzheimer's Association. Breakout sessions for each of the seven (7) recommendations identified action steps for the implementation of the Plan. Due to the number of goals and strategies, the level of detail reported varied. This report provides a high-level overview of the concepts and discussions from the breakout sessions.

The Pennsylvania Department of Aging is confident the outcomes and partnerships established during this Forum will generate a continued movement forward to implement the Plan for a thoughtful, integrated and cost effective approach to addressing the needs of persons with Alzheimer's Disease and Related Disorders in the Commonwealth of Pennsylvania.

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<sup>1</sup> The Plan is available on the Department of Aging's web site, at [www.aging.pa.gov](http://www.aging.pa.gov)

## **II. Introduction**

The State Plan for Alzheimer's Disease and Related Disorders Forum consisted of a diverse group of individuals comprised of government leaders, providers, associations, academia, research, bio industry, consumers and other individuals engaged in ADRD activities. The purpose of the Forum was to foster discussion and develop strategic action steps for implementing the ADRD Plan.

Participants were asked to select a breakout session based on their personal interest. The main charge given to each breakout group during the two hour sessions was to identify action steps which could help carry out the goals supporting each of the seven recommendations.

Direction and instruction for facilitators was provided by the Department through a facilitators guide.

The participants at sessions were asked to:

- Discuss any related activity, programs or services which stakeholders may be aware of which are addressing the recommendations
- Identify at least one short term and one long term action step for each goal and/or strategy and
- Identify key partners and collaborations needed to accomplish the goals and strategies.

The facilitators asked participants to keep in mind both current financial realities, and ways to identify new resources.

The action steps are described in Section V.

### **III. Recommendations**

**The following are the recommendations from the Pennsylvania State Plan for Alzheimer 's Disease and Related Disorders:**

1. Improve awareness, knowledge, and sense of urgency about medical, social, and financial implications of Alzheimer's disease and related disorders (ADRD) across the commonwealth.
2. Due to the magnitude of the ADRD epidemic, identify and where possible, expand financial resources to implement this plan through federal, state, foundation, private and other innovative funding mechanisms and partnerships.
3. Promote brain health and cognitive fitness across the life cycle from birth onward.
4. Provide a comprehensive continuum of ethical care and support that responds to social and cultural diversity, with services and supports ranging from early detection and diagnosis through end-of-life care.
5. Enhance support for family and non-professional caregivers and those living with ADRD.
6. Build and retain a competent, knowledgeable, ethical, and caring workforce.
7. Promote and support novel and ongoing research to find better and effective cures, treatments, and prevention strategies for ADRD.

#### **IV. Agenda**

The First Annual Pennsylvania Alzheimer's Disease and Related Disorders Forum opened with remarks from Secretary Brian Duke who welcomed over 150 attendees and introduced a video from Governor Tom Corbett welcoming the participants.

The Governor introduced the scope and purpose of the day and that the First Annual Forum serves as an opportunity to help the over 400,000 Pennsylvanians living with Alzheimer's Disease or a related disorder and their caregivers. Governor Corbett thanked all attendees for taking part in this landmark occasion.

The Forum was held in conjunction with World Alzheimer's Day which is dedicated to raising awareness of the disease in order to fight for a cure. To build upon the importance of the day, Secretary Duke highlighted the *Memories in the Making* art exhibit which lined the walls of the main meeting room. The art was made possible by the Delaware Valley Chapter of the Alzheimer's Association and demonstrates a unique program that allows those living with Alzheimer's disease or a related disorder to express themselves through art. The *Memories in the Making* art program began in 1988 and throughout the day, attendees were encouraged to view the art and reflect upon the importance of the program.

To fortify the attendees' role for the day, Pennsylvania State Representative Tim Hennessey, Chair of the House of Representatives Aging and & Older Adult Services Committee and Pennsylvania State Senator Randy Vulakovich, Chair of the Senate Aging and Youth Committee gave remarks. Chairmen Hennessey focused on the deliberations of the committee and summed the Forum's purpose by stating that the Forum was "bringing the best of Pennsylvania, to all Pennsylvanians". Chairmen Vulakovich stressed the importance of the day by stating that the actions steps identified are the avenue to ensure the Pennsylvania State Plan for ADRD is implemented and serves those Pennsylvanians who need it most.

After the chair's remarks, Secretary Duke then discussed some of the most recent accomplishments after the State Plan for Alzheimer's Disease and Related Disorders was submitted to the Governor in February 2013. These accomplishments included the work of the Pharmaceutical Assistance Contract for the Elderly (PACE) academic detailing program. In the spring of 2014, PACE physicians and pharmacist began a systematic and comprehensive review of the medication regimens of 30,000 PACE enrollees who have been diagnosed with Alzheimer's disease or a related disorder. This included a new module that would help physicians and other health care providers properly diagnose and treat Alzheimer's disease. A second module by the PACE behavioral health intervention team focused on offering counseling and technical assistance to caregivers of PACE enrollees who have been diagnosed with Alzheimer's disease. It is anticipated that up to 200 people will be assisted each month. Other accomplishments included a revised Level of Care Determination (LCD) tool to better identify individuals' needs and identify services. Revised Care management is also included to improve the functioning and wellbeing of older adults with ADRD and their informal caregivers.

After the overview of accomplishments, Secretary Duke introduced the purpose of the breakout sessions and the breakout session facilitators. (See Section V. detailed breakout session information) The attendees then broke into the seven breakout sessions.

When the attendees reconvened at lunch, the action steps from the breakout sessions were shown to all attendees. Attendees had the opportunity to review their work and the work of other sessions.

At the conclusion of lunch, Barbara Overholser, Editor of *makingsenseofalzheimers.org*, presented on the *Making Sense of Alzheimer's* project which is described as “a creative space for people to understand the past, present and future of Alzheimer’s disease. It is an evolving forum, a gallery of ideas, a museum without walls.” Ms. Overholser provided a walkthrough of the *Making Sense of Alzheimer's* website and encouraged all attendees to learn more about the project.

Following *the Making Sense of Alzheimer's* presentation, Randi Chapman, Director of State Affairs for the Alzheimer’s Association provided the keynote address. Her presentation (see appendix B) entitled “So You’ve Got a State Plan... Now What?” focused on the differentiating types of State Plans from across the United States. The address gave the attendees a snapshot of the work of the National Alzheimer’s Association and stressed the importance of bringing the over 40 State Plans to implementation. Ms. Chapman cited the work of Colorado, Massachusetts, Oregon, Florida, New Mexico, Texas, Virginia and Minnesota and highlighted the different stages in the planning and implementation process.

The day concluded by with a final address from Secretary Duke. Secretary Duke thanked all attendees, facilitators and Department of Aging staff and reiterated that the action steps developed during the Forum and highlighted in this report will guide the Department of Aging through the implementation process.

## **V. Proposed Action Steps**

**The following is a summary of some of the action steps identified by the participants:**

**RECOMMENDATION #1: Improve awareness, knowledge, and sense of urgency about medical, social, and financial implications of Alzheimer’s disease and related disorders (ADRD) across the commonwealth.**

**Facilitators – Michael Ellenbogen, Author and Advocate living with Alzheimer’s Disease  
Robert Marino, Co-Chair, Pennsylvania Public Policy Coalition, Delaware  
Valley and Greater Pennsylvania Chapters of the Alzheimer’s Association**

**Session Attendees:**

Julia Brinjac, Public Policy Coordinator, Pennsylvania Chapters of the Alzheimer’s Association

Connie Brode, Acting Executive Director, Huntingdon/Bedford/Fulton Area Agency on Aging

Jean Carlstadt, Secretary, Pike County Area Agency on Aging Advisory Board

Rev. George Gunn, Member, Pennsylvania Council on Aging, retired CEO and founder-  
ACTS Retirement Communities

Daniel Haimowitz, MD, FACP, CMD, Geriatrician and Medical Director LIFE Saint Mary

Steve Kelly, Regional Manager Harrisburg, Senator Pat Toomey

Tara Kramer, Executive Assistant, Hersha Hospitality Trust

Brian Long, Pennsylvania LINK to Aging and Disability Resources, Berks-Lancaster-  
Lebanon Service Area Coordinator

Jen Martchek, Member Pennsylvania Council on Aging and Board Southwestern  
Pennsylvania Partnership for Aging

Bonnie Mountz, Manager Finance and Administration, Pennsylvania Statewide  
Independent Living Council

Sandy Murphy, Director, Chester County Area Agency on Aging

Marcela Myers, Director, Pennsylvania Center for Practice Transformation and  
Innovation Pennsylvania Department of Health

JoAnn Nenow, Executive Director, Meals on Wheels of Northampton County

Barbara Overholser, Coordinator, Penn Memory Center at University of  
Pennsylvania

Erin Raub, Research Analyst, Pennsylvania House Aging and Older Adult Services Committee

Frances Reaman, Member Pennsylvania Council on Aging

Matthew Sharp, Program Manager, The Association for Frontotemporal Degeneration

Nathan Silcox, Legislative and Communities Director, Senate Aging and Youth Committee

Eric Harkreader, Marketing Assistant, Pennsylvania Department of Aging

Lauren Merlie, Policy Director, Pennsylvania Department of Aging

Breakout session one opened with facilitator Bob Marino expressing the need to keep the momentum of the State Plan for Alzheimer's Disease and Related Disorders work flowing. Many other states, like Pennsylvania, have started down the necessary path of changing the course of this disease. It requires making hard choices, allocating money, engaging numerous groups of individuals and keeping the conversation relevant and ongoing. That being said, the group was tasked with how to best engage and educate the commonwealth on ADRD. By having the inaugural Forum, participants could see that a goal of recommendation one was already being accomplished. The group was most passionate about raising ADRD awareness and knowledge to the public, community and business leaders, healthcare providers and the aging network, to name a few. It was determined that a public awareness campaign across the commonwealth is needed in order to educate all persons touched by ADRD. The group also had an in depth conversation on why ADRD should be recognized as a chronic disease and a public health issue.

#### Goal 1A:

Determine baseline and outcome data regarding the prevalence and demographic characteristics of Pennsylvanians with ADRD, including age of onset, comorbid conditions, and prevalence of risk factors, use of medications, and health inequities and disparities.

- ✓ Action Step: By 2015, conduct a wide scale Behavioral Risk Factor Surveillance System (BRFSS) survey with at least one of the two Alzheimer's modules (cognitive & caregiver impact) to more precisely gauge the number of Pennsylvanians with ADRD.
- ✓ Action Step: Work with the lead agency, Pennsylvania Department of Health to find out a way to prioritize funding that would include the addition of these modules and ultimately implementation.
- ✓ Action Step: Conduct BRFSS surveys on an annual basis to obtain baseline data with the intention of moving to bi-annually to be mindful of costs.

### Goal 1B:

Determine the economic impact of ADRD in Pennsylvania.

- ✓ Action Step: Set baseline data on the incidence rate of ADRD in PA.
- ✓ Action Step: Conduct internal audit of data related to persons living with ADRD and their caregivers including Medicare expenditures, and loss of productivity reported by Labor & Industry.
  - Correlate this data with the BRFSS findings and begin to determine the economic loss due to ADRD.

### Goal 1C:

Reduce the stigma associated with ADRD by raising awareness and knowledge among the public with key message that living well with ADRD is an attainable goal.

- ✓ Action Step: Develop and conduct a Public Service Announcement forming a key message that reaches those impacted by ADRD.
  - Replicate previous successful public health campaigns. An example could be campaigns which encouraged people to quit smoking. The message was conveyed by major corporations which sent their employees to presentations. A uniform message was used. Another possible means of outreach could be to utilize PennDOT signs to provide key messages to the public.
- ✓ Action Step: Gather business partners and community leaders who have an ADRD interest.
  - Engage them as messengers, have their entities spread the Public Service Announcement.

### Goal 1D:

Raise ADRD awareness and knowledge among health-care providers, public health professional and aging services providers.

- ✓ Action Step: Work with Pennsylvania Department of Health to make ADRD education a license/accreditation requirement.
- ✓ Work with other partners including the Pennsylvania Medical Society, Alzheimer's Association & Hospital & Healthsystem Association of Pennsylvania (HAP) to develop and promote an education requirement.
- ✓ Action Step: Work with the Pennsylvania Department of Health to elevate ADRD to a chronic condition and identify as a public health issue.
- ✓ Action Step: Work with Pennsylvania's medical schools to encourage more education on ADRD.

### Goal 1E:

Improve information sharing regarding treatment and risk reduction options (including the goals discussed in recommendation 3) for ADRD with residents of Pennsylvania to improve quality of life and patient outcomes.

- ✓ Action Step: Incorporate ADRD among topics for public health grants from federal sources.
- ✓ Action Step: Make public ADRD information easy to find and accessible with information on other key chronic diseases.

### Goal 1F:

Promote and support the development of dementia friendly communities to empower individuals with ADRD and their caregivers and to combat stigma.

- ✓ Action Step: Start with training those with the most public touch points to recognize signs of ADRD to both encourage people to get evaluated for ADRD and also to be sensitive to what needs ADRD people have.
- ✓ Action Step: Educate dispatchers/first responders so that they are better educated as to the needs of a person living with ADRD and their caregiver. Collaborate on the experience of caregivers during emergency response in situations which may not warrant an aggressive 911 approach.

### Goal 1G:

Improve the safety of individuals with ADRD in communities across the commonwealth.

- ✓ Action Step: Improve use of the Pennsylvania Missing Endangered Person Advisory (MEPA) System. Empower first responders, via information from 911 databases and voluntarily submitted information from public health databases, to quickly access information on those with ADRD.
- ✓ Action Step: Give GPS trackers to ADRD patients.
- ✓ Action Step: Adopt other effective programs such as Alzheimer Safe Return, Project Lifesaver.

- ✓ Action Step: Approach county commissioners and other county leaders to use MEPA best practices.

Goal 1H:

Protect individuals with ADRD from abuse and financial exploitation using guidance from key federal and state agencies.

- ✓ Action Step: Engage financial institutions and their state associations to develop stronger relationships with Area Agencies on Aging and other service providers and work with other agencies such as Attorney General's office and Banking & Securities.

Goal 1I:

Convene annual Pennsylvania Alzheimer's Plan Summit meetings to evaluate progress on the Plan, strengthen partnerships, build community support for the Plan, recognize excellence, and identify next steps.

- ✓ Action Step: Continue and encourage annual Forums.
- ✓ Action Step: Sync Department of Aging Forum with World Alzheimer's Day in September (this may help retain legislative participation and funding).
- ✓ Action Step: Extend the length of breakout sessions to allow for more time to evaluate the Plan's progress and have more detailed and in depth discussions.
- ✓ Keep the State Plan for ADRD a living document and integrate with the State Plan on Aging.

**RECOMMENDATION #2: Due to the magnitude of the ADRD epidemic, identify and where possible expand financial resources to implement this plan through federal, state, foundation, private, and other innovative funding mechanisms and partnerships.**

**Facilitator – Kathy Jedrzewski, PhD, Deputy Director, Institute on Aging University of Pennsylvania**

**Session Attendees:**

Jacqueline Burch, Executive Director, Lancaster County Office of Aging

Veronica Comfort, Member, Pennsylvanian Council on Aging

Franca Maria D’Agostino, Director, Special Projects, Pennsylvania Insurance Department

Nicole Fedeli-Turiano, Director of Public Policy and Government Relations for UPMC Community Provider Services Division

Kathy Gillespie, Administrator, Clearfield County Area Agency on Aging

Georgia Goodman, Executive Assistant, Pennsylvania Department of Public Welfare

Beth Greenberg, Director of Regulatory Affairs, LeadingAge PA

Clayton Jacobs, Vice President Programs and Services, Greater Pennsylvania Chapter, Alzheimer’s Association

Jennifer Kostasich, MPH, Senior Policy Analyst, AmeriHealth Caritas

Najja Orr, Director, Bucks County Area Agency on Aging

Karen Sheriff, Administrator, Perry County Area Agency on Aging

Brian Smith, Director Clinical Compliance and Quality, Hospital and Healthsystem Association of Pennsylvania

Julie Thomas, Early Stage and Advocacy Coordination, Delaware Valley Chapter, Alzheimer’s Association

Wilmarie Gonzalez, Long Term Care Ombudsman and Director Bureau of Advocacy, Pennsylvania Department of Aging

Evelyn Chianelli, Special Assistant, Pennsylvania Department of Aging

Due to the breadth of existing resources and potential resources that may be available in order to meet this goal, the group’s one major recommendation was the designation of a state level coordinator. This position would be responsible in forming a comprehensive network of

stakeholders representing academia, foundations, private and public sector organizations, including community-based organizations that could help coordinate and identify resources and support systems specifically to support ADRD initiatives. This would include identifying funding opportunities, existing and upcoming research in support of ADRD, and identifying best practices from other states or organizations that Pennsylvania could replicate to strengthen the state plan.

#### Goal 2A:

Review and maximize utilization of existing financial resources to ensure that individuals with ADRD receive care in the most appropriate and cost-efficient setting.

- ✓ Action Step: Identify state level coordinator to:
  - Identify funding opportunities from sources and know the players who might be interested in applying for funding and connect them.
  - Review how state resources are spent; consult with key stakeholders and make recommendations for cost effective changes, including addressing gaps in services.
  - Look to other states for models and best practices for care.

#### Goal 2B:

Develop and/or promote programs to encourage research and technology development in the area of ADRD.

- ✓ Action Step: Create a more favorable business climate for ADRD research and technology (including appropriate tax incentives).
- ✓ Action Step: Create of a task force of key stakeholders (i.e., academia, foundations, private and public sectors) to coordinate what is currently available and make recommendations
  - Community outreach/education regarding impact of ADRD (private sector, foundation, medical providers, etc.).
  - Marketing targeted to consumers to utilize new technology and enhance awareness of development; the increased utilization of technology could have the potential to bring more resources to the state.
  - Develop ways to measure the impact.

#### Goal 2C:

Identify and implement innovative funding mechanisms to support research aimed at finding cures, treatments, and prevention strategies for ADRD.

- ✓ Action Step: Charge ADRD state level position with coordinating ADRD activities including:
  - Identification of sources of funding including existing foundations/private sectors and matching possible sources with the needs of key stakeholders.
  - Creation of partnerships (existing and future; task force, groups, i.e., Aging Disability Research Centers and others)
  - Formation of collaborations among organizations carrying out the research.
  
- ✓ Action Step: ADRD Planning Committee and future implementation advisors should reach out to private industry and to each other and share activities.

Goal 2D:

Develop collaborative public-private investments in awareness campaigns, education, services, and caregiver support.

- ✓ Action Step: Advocate moving forward with legislation that would allow for Medicare, Medicaid, and private insurance reimbursement in ADRD care. Improve coding and billing to support for physicians, other healthcare providers and wellness programs to receive payment for ADRD related services.
  
- ✓ Action Step: Identify and engage the support of non-traditional partners (such as utility companies, insurance providers, health plans, sports teams, billboard companies, banks, and agricultural extension offices) in disseminating educational materials and resources that foster public awareness of ADRD and services available.
  - For example, United Way of the Greater Lehigh Valley has a “gate keeper program” that is training non-traditional referral sources to identify older consumers at risk and connect them to local services which help them remain safe and independent in their homes.

Goal 2E:

Advocate for increased federal support for ADRD research.

- ✓ Action Step: Pennsylvanian associations and support groups related to ADRD as well as individual constituents advocate to their federal legislators for additional support in ADRD research.
  - Utilize PA demographics to make case.
  - Educate citizens in support of the ADRD effort.

- Leverage current Alzheimer's Association initiative via website [www.alz.org/advocate](http://www.alz.org/advocate).
  - Work with current providers of ADRD services to see what they are doing to help advocate.
- ✓ Action Step: Engage legislators in visits to Pennsylvania's institutions conducting and implementing ADRD research.

**RECOMMENDATION #3: Promote brain health and cognitive fitness across the life cycle from birth onward.**

**Facilitator – Brian Duke, Secretary PA Department of Aging**

**Session Attendees:**

Crystal Lowe, Executive Director, Pennsylvania Association of Area Agencies on Aging

Terry Barley, Director, Cumberland County Aging and Community Services

Jeffrey Dauber, Education and Outreach Coordinator, Greater Pennsylvania Chapter, Alzheimer's Association

Claire Day, Senior Vice President, Delaware Valley Chapter, Alzheimer's Association

Georgene Fedoriska, Executive Director, Schuylkill County Office of Senior Services

Serina Gaston, Director, Division of Nutrition and Physical Activity, Pennsylvania Department of Health

Daniel George, Ph.D., Assistant Professor, Department of Humanities, Penn State College of Medicine

Patti Gozikowski, Director of Active Adult Center Services, Area Agency on Aging for Luzerne-Wyoming Counties

Tigist Hailu, Coordinator for Diversity in Research, Penn Memory Center , University of Pennsylvania, Perelman School of Medicine

Vicki Huffaker, Executive Director, Adams County Office for Aging Inc.

Robin LoDolce, Executive Director, Pike County Area Agency on Aging

David Maciukiewicz, Director, Personal Care, Brookdale Senior Living

Melissa Myers, Democratic Executive Director, Pennsylvania House Aging and Older Adult Services Committee

Gelene Nason, Senior Supportive Housing Officer, Pennsylvania Housing Finance Agency

Susan Getgen, Director, Bureau of Quality Assurance, Pennsylvania Department of Aging

Debee Ethridge, Clerk, Pennsylvania Department of Aging

The overarching theme was that Pennsylvania is facing a national public health issue with the growing incidence of ADRD. The participants felt that there is a need for a message regarding brain health and cognitive fitness but it needed to be appropriate in reflecting that even though an individual follows all the recommendations for a healthy life style, they may still develop ADRD. Brain health also needs to be defined. Credible resources and collaboration is imperative to move forward and evidenced based initiatives need to be promoted. Overall, to make an impact, Pennsylvania needs to promote that living a healthy life style is good for a healthy brain starting early in the lifecycle, messaging needs to be clear and concise, and social media should be utilized for engagement.

#### Goal 3A:

Potentially delay the onset of ADRD by promoting brain health and cognitive fitness.

- ✓ Action Step: Promote consistent realistic simple messages through an awareness campaign that lifelong healthy living equals brain health, identify and engage traditional and non-traditional strategies for all cultures and ethnicities and inventory and promote valid resources.

#### Goal 3B:

Build capacity to promote brain health through partnerships among government agencies, patient advocacy organizations, health care systems, academic institutions, and payers (e.g. insurance companies and Medicare).

- ✓ Action Step: Develop a definition of brain health and promote the message that brain health is a public health issue at any stage of life. Social media should be utilized to engage in a rudimentary educational message that everyone can relate to. This can be a passive message to incorporate healthy living into a simple, understandable message as the key to brain health.

**RECOMMENDATION #4: Provide a comprehensive continuum of ethical care and support that responds to social and cultural diversity, with services and supports ranging from early detection and diagnosis through end-of-life care.**

**Facilitator – Kelly Carney, PhD, CMC, Dementia Center for Excellence for Phoebe Ministries**

**Session Attendees:**

Linda Arcurie, CHPN, Director of Clinical Services, VNA Hospice and Home Health of Lackawanna County

Ron Barth, President/CEO, LeadingAge PA

Kerry Brown, Associate Director, Clinical Services, Delaware Valley Chapter, Alzheimer's Association

Quentin Burchfield, Case Worker Supervisor, Dauphin County Area Agency on Aging

Frank Byrne, President and CEO, Pennsylvania LIFE Provider Alliance

Kathy Cubit, Director of Advocacy Initiatives, CARIE

Krista DiRienzo, Community Relations Specialist, VNA Hospice and Home Health of Lackawanna County

Glen Dunbar, Adjunct Professor, Sociology, Harrisburg Area Community College

Stephen Feldman, Member, Board of Directors, Delaware Valley Chapter, Alzheimer's Association

Gerry Fioriglio, President, Family Caregivers Network

Mary Kandray Gelenser, Grants Manager, Center for Rural Pennsylvania

Owen Lavery, Consultant, Pennsylvania Adult Day Services Association

Bill Orzechowski, Director, Office of Human Services Inc. (Cameron, Elk and McKean Counties Area Agency on Aging)

Fredericka Waugh, Afri Outreach Coordinator, Delaware Valley Chapter, Alzheimer's Association

Stephanie Quigley, Nursing Home Transition Program Director, Abilities in Motion

Paul McCarty, Executive Director, Intra-Governmental Council on Long Term Care, Pennsylvania Department of Aging

Kellie Kask, Executive Assistant, Pennsylvania Department of Aging

The discussion focused on the need to assess how ADRD is affecting the state as a whole through partnering with various institutions such as universities and not-for-profit hospitals. Input from stakeholders is needed to define and determine the tools necessary to assess the current strengths, gaps, and barriers within the continuum of care in its ability to support individuals with ADRD and their caregivers. Ideas shared included the credentialing of care managers who serve individuals with ADRD and their caregivers; the distribution of pertinent information widely to organizations that are serving both those living with ADRD, as well as, those providing treatment and services. There is a need for an information clearinghouse for best practices, innovative programs and training, and faster access to home and community supports and services.

Goal 4A:

Assess the current strengths, gaps, and barriers within the continuum of care of each Pennsylvania county in its ability to support all individuals with ADRD and their caregivers.

- ✓ Action Step: Pull together professional organizations such as the Hospital and Healthsystem Association of Pennsylvania (HAP), academia and others regarding ADRD data.
- ✓ Action Step: Partner with not-for-profit hospitals and other organizations to ensure ADRD needs are assessed, uniformity is encouraged and there is collaboration in ADRD care guidelines.

Goal 4B:

Develop a plan to address the identified gaps in the continuum of care, including, but not limited to, adult day services, palliative care, end-of-life care, transportation, private duty, respite care, and other home and community-based services.

- ✓ Action Step: Expedite eligibility process for waiver services.
- ✓ Action Step: Request Medicare demonstration to use palliative care to enable individuals to age in place.

Goal 4C:

Expand availability of and access to care management services in order to coordinate services for individuals with ADRD living in settings across the continuum of care.

- ✓ Action Step: Identify and utilize best practices in care coordination.

#### Goal 4D:

Increase the early detection and diagnosis of ADRD by promoting the assessment of cognitive health and depression.

- ✓ Action Step: Contact and collaborate with primary care physicians, associations and health care providers to provide cognitive health and depression assessments during annual routine physical exams and promote inclusion in care guidelines for medical homes, Accountable Care Organizations and other models of care.

#### Goal 4E:

Improve quality of life, safety and cost of care by maintaining individuals with ADRD in the most appropriate and cost-effective settings.

- ✓ Action Step: Link with partners such as academic institutions, Aging Institutes, foundations, etc. to assess current care and identify an agenda for moving forward.

#### Goal 4F:

Promote innovation in service systems and funding mechanisms related to the care of individuals with ADRD, including underserved populations and those in rural communities of the commonwealth, which improve quality of care and support, enhance quality of life, create efficiencies, and reduce costs.

- ✓ Action Step: Recommend that ADRD innovation be included in State Innovation Model grant.
- ✓ Action Step: Work with both the PA Long-Term Care Commission and the Joint State Government Commission to ensure that efforts are not duplicated and to maximize the success of improving quality of care, support, quality of life, creating efficiencies and controlling costs.

**RECOMMENDATION #5: Enhance support for family and non-professional caregivers and those living with ADRD.**

**Facilitator – Beth Herold, Director Butler County AAA**

**Session Attendees:**

Alexa Burns, Social Service Coordinator, Pleasant Acres Nursing and Rehabilitation Center

Wendy Campbell, President, Delaware Valley Chapter, Alzheimer's Association

Gina Cooke, Director, Diakon

Art DiLoreto, Deputy Director, Pennsylvania Association for Area Agencies on Aging

Margie Hoffman, Executive Director, HCR ManorCare Linden Village

Barry Jacobs, Psy.D, Director of Behavioral Sciences, Crozer-Keystone Center for Family Health

Cynthia Lambert, M.Ed., Vice President, Good Shepherd Rehabilitation

Karen Leonovich, Deputy Administrator, Northumberland County Area Agency on Aging

Kathleen Lynn, Executive Director, Columbia/Montour Area Agency on Aging

Diane Menio, Executive Director, Center for Advocacy for the Rights and Interests of the Elderly (CARIE)

Leslie Mundis, Pleasant Acres Nursing & Rehabilitation Center

Lisa Perugino, RN, BSN, Erwine Home Health & Hospice

Gail Roddie-Hamlin, President, Greater Pennsylvania Chapter, Alzheimer's Association

Jennifer Smith, Executive Director, HCR ManorCare Arden Courts of Susquehanna

Denise Stewart, Director, Delaware County Office of Services for the Aging

Ransom Towsley, Senior Director of Community Services, Presbyterian Senior Care

Elsie Viehman, Volunteer Ambassador, Delaware Valley Chapter, Alzheimer's Association

Linda Zadorozny, Delaware Valley Chapter, Alzheimer's Association

Steven Zarit, Distinguished Professor, Department of Human Development and Family Studies, The Pennsylvania State University

Donna Zimmerman, Director, Lehigh County Office of Aging and Adult Services

Donna Reinaker, Executive Director, Pennsylvania Council on Aging, Pennsylvania Department of Aging

Stephanie Cole, Aging Services Specialist, Pennsylvania Department of Aging

Two themes emerged during breakout session #5. The first being, even though there are tools and information for family and non-professional caregivers, improvements are needed regarding the access and availability to this information in order to increase utilization. Secondly, a key to the success of enhancing support for family and non-professional caregivers and those living with ADRD is the collaboration of primary care doctors, social workers, patients and caregivers using a multidisciplinary approach to create an educational and training network.

#### Goal 5A:

Conduct an assessment of caregiver needs, including, but not limited to, legal and financial guidance, respite care, psychological counseling, and stress management.

- ✓ Action Step: Create an assessment tool by studying existing assessments, using available research and statistics.

#### Goal 5B:

Provide resources and support that will better enable informal (i.e. non- professional) caregivers to care for their loved ones and themselves.

- ✓ Action Step: Identify and categorize current, available statewide and national resources. Assess gaps in types of information and resources. Determine ways to better use technology to enhance access.
- ✓ Action Step: Create family centered programs while partnering with hospitals, faith based organizations and Veterans Service Organizations.
- ✓ Action Step: Encourage the establishment of additional caregiver support groups in geographical areas of the commonwealth that currently lack such groups and formal support. A partnership with the Area Agencies of Aging (AAA) to provide information by county would improve data sharing and identification of areas of need.

- ✓ Action Step: Explore the feasibility of legislation to provide financial support to caregivers while working with the PA Department of Aging's legislative and policy offices.

#### Goal 5C:

Address the unique needs of those living with ADRD.

- ✓ Action Step: Improve and expand services for individuals living with ADRD to reduce the large gaps that currently exist with services.
- ✓ Action Steps: Enhance the use of tele care and assistive technology.
- ✓ Action Steps: Educate volunteers to provide information helpful to individuals as they make decisions and ensure that home environments are adequate to receive services.
- ✓ Action Steps: Create awareness of services for those living alone with ADRD by developing a white paper regarding this subject to raise attention in the state and nationally.

#### Goal 5D:

Provide training and education for non-professional caregivers and those living with ADRD.

- ✓ Action Step: Disseminate caregiver tools by using the assistance of grassroots organizations, places of worship and physician offices so this support is effectively disseminated throughout the community.
- ✓ Action Step: Create a network using professional cohorts utilizing an interdisciplinary approach to develop an educational program for caregivers that would provide a culturally sensitive and adaptable training.
- ✓ Action Step: Improve linkages between the medical care team and informal caregivers by using social media to strengthen lines of communication to ultimately improve training and education.

**RECOMMENDATION #6: Build and retain a competent, knowledgeable, ethical, and caring workforce.**

**Facilitator – Heidi Owen, Director of Hospice/Oncology, Neighborhood Health Agencies, Inc.**

**Session Attendees:**

Dr. Noel H. Ballentine, MD, FACP, Associate Professor of Medicine, Penn State College of Medicine

Mia Bartoletti, Vice President, Caregivers America, LLC

Kellie Butsack, Associate Director Programs Delaware Valley Chapter Alzheimer's Association

Jen Drescher, Regional Director of Operations HCR ManorCare Arden Courts of Susquehanna

Linda Drummond, Policy Specialist, Pennsylvania Community Providers Association

Chris Dubble, Director, Temple University School of Social Administration & Institute on Protective Services

Brenda Hage, PhD, Director of Doctor of Nursing Practice ( DNP) Programs and Member, Pennsylvania Council on Aging

Sue Heinle, RN, Owner and President, Visiting Angels of York

Tina Hess, BS, CMC, CCG, Owner, Good News Consulting

Rebecca May-Cole, Co – Chair, Pennsylvania Adult/Older Adult Suicide Prevention Coalition

Krista McKay, MPA, Delaware Valley Chapter Alzheimer's Association

Matthew Perkins, Vice President, Service Coordination Unlimited

Amy Szydowski, District Executive Director, Pennsylvania Department of Health

Candy Yingling, Education and Outreach Coordinator, Alzheimer's Association Greater Pennsylvania Chapter

Steven Horner, Director, Bureau of Aging Services, Department of Aging

Bridget Hinkle, Aging Services Supervisor, Department of Aging

The participants of the breakout session identified that there are some existing resources currently available to educate, build, and retain a competent, knowledgeable, ethical, and caring workforce for physical and behavioral health care professionals at all levels of care about the needs of persons with ADRD. There is a need for a process to review and evaluate existing resources and curricula in order to determine appropriateness and relevance. A centralized web-based clearinghouse of information should be developed which identifies training opportunities and categorizes information. This would increase access to information, participation in training, and knowledge about caring for individuals with ADRD. A strategy is needed to incorporate ADRD training in licensing regulations across the continuum of care. This could include offering continuing education units, and specifying training requirements for re-licensure in each discipline. Training should include education programs for those working in home and community based settings and forum licensed personnel within the health and long term care facilities. A desired outcome would see educational programs which do not impose a need for additional work hours. Workforce capacity to care for the quickly growing elderly population will require the marketing and advertisement of career opportunities in the care of persons living with ADRD. There should be an emphasis on the positive and rewarding aspects of the work. Outreach should also highlight innovations such as career ladders and opportunities for advancement. Partnerships with schools and universities to promote mentorships, traineeships and shadowing programs should be developed in order to encourage individuals to pursue and remain in careers in ADRD care. There should also be a vital focus on, incentives such as scholarships/grants opportunities and loan forgiveness programs.

#### Goal 6A:

Educate physical and behavioral health care professionals at all levels of care about the unique needs of persons with ADRD.

- ✓ Action Step: Develop a web-based clearing house of information regarding training opportunities, including training in ethical considerations related to ADRD.
  - Include sub-types within clearinghouse that would break down training by discipline (Physicians, professionals, home caregivers, facility staff, mental health delegates and judges).
- ✓ Action Step: Identify a company to develop, implement, and maintain web-based system described above.
- ✓ Action Step: Notify and educate coalitions and industry agencies/personnel of the web based system described above.

#### Goal 6B:

Encourage professionals to pursue and remain in careers in ADRD care.

- ✓ Action Step: Identify and implement career ladders and opportunities for advancement.
- ✓ Action Step: Create recognition/rewards for individuals who are trained in this skill set.

- ✓ Action Step: Develop mentorship programs, support groups, and other avenues to promote professionalism in this field.
- ✓ Action Step: Develop shadowing program for high school/college students to gain exposure to the career.
- ✓ Action Step: Encourage higher education institutions to include geriatric “tracks” or specializations.
- ✓ Action Step: Examine existing programs (ex: Child Welfare Education for Leadership CWEL) to determine applicability to this population.

**RECOMMENDATION #7: Promote and support novel and ongoing research to find better and effective cures, treatments, and prevention strategies for ADRD.**

**Facilitators – David Leader, President and CEO, Providence Place Senior Living**

**Mickey Flynn, Former PA Bio President**

**Session Attendees:**

Ann Barlet, Manager Community Outreach and Education, Berks County Area Agency on Aging

Christopher Beck, Associate Director of Government Relations, Perelman School of Medicine University of Pennsylvania Health System

Mel Billingsley, Ph.D., President, Life Sciences Greenhouse of Central Pennsylvania

Roger Cadieux, MD, PACE/PACENET Program, Pennsylvania Department of Aging

Susan Cerrito, Delaware Valley Chapter, Alzheimer's Association

Lawrence Cerrito, Jr., Delaware Valley Chapter, Alzheimer's Association

Anna Lisa De Obaldia, Graduate Student, Pennsylvania State University College of Medicine

Lynn Fields Harris, Executive Director, Center in the Park

Mitchel Kling, MD, Associate Professor of Psychiatry at the Hospital of the University of Pennsylvania and the Veteran's Administration Medical Center

Carol Lippa, MD, Professor and Interim Chair, Department of Neurology, Drexel University College of Medicine

Marnie McCoy, Program Director, BioAdvance

Barbara O'Malley, Acting Director, Montgomery County Office of Aging and Adult Services

Domenico Pratico, MD, Professor, Center for Translational Medicine, Temple University School of Medicine

Melisa Rader, Policy Specialist, Pennsylvania Department of Health

Hank Safferstein, Ph.D, JD, Executive Director, Cognition Therapeutics, Inc.

Mary Vaughn, Executive Administrative Assistant, Wyeth Pharmaceuticals

Terry Brown, Program Analysts, Pennsylvania Department of Aging

Diane Eshelman, Director, Bureau of Human Resources , Pennsylvania Department of Aging

Members of the breakout session spoke about the need for collaborative information sharing at multiple levels that would connect research institutions, biotechnology companies, commercial and non-profit medical services providers, and the general public. Although Pennsylvania has several organizations doing outstanding work in ADRD, it lacks a statewide leadership group that would work to create a powerful, recognized statewide collaborative research network. With a statewide network, the members thought Pennsylvania would be well-situated to become a national leader in research initiatives and patient recruitment. This would give support to the work of the existing urban centers and expand to the rural health care organizations, thus reaching all communities of the state. The participants agreed that a positive outcome of the meeting would be to identify the leaders in the ADRD field who were present at the sessions and ask them to begin work to develop a Pennsylvania statewide center of excellence for ADRD research. Identify and research other states that have provided incentives for biomedical technology companies working in ADRD. Investigate how Massachusetts administered tax credits and how California provides grants for research that are beyond the scope of National Institute of Health funding.

#### Goal 7A:

Promote participation in clinical trials, ensuring inclusion of underserved and rural populations.

- ✓ Action Step: Solicit participation and launch a commonwealth focused clinical trial website (free standing, not embedded in state portal) and collaborative information sharing; precompetitive with social media component and promotional campaign addressed to many audiences.

#### Goal 7B:

Promote Pennsylvania as a magnet for clinical research by developing a network of hospital and other health care providers with clinical research capability across the commonwealth.

- ✓ Action Step: Identify who they are, bring together, develop a link to share with the community at large the capabilities across the state (prospective outreach message) and educate the general public about participation.

#### Goal 7C:

Cultivate collaborative efforts of the research, clinical, pharmaceutical, regulatory, and payer communities to identify barriers and solutions at each stage of treatment development with the goal of producing novel methods to prevent and treat ADRD.

- ✓ Action Step: Expand the ADRD Forum to gather the appropriate parties that could form, for example, a statewide center of excellence for ADRD research, gathering them annually.

Goal 7D:

Provide incentives for biomedical technology companies working in the ADRD field to remain in or relocate to Pennsylvania.

- ✓ Action Step: Identify states and learn from existing programs/incentives that have been instituted and determine appropriate incentives for PA utilizing the Battelle/Bio study.

**Appendix A. Pennsylvania Alzheimer’s Disease and Related Disorder Forum Agenda**

**Pennsylvania State Plan for  
Alzheimer’s Disease and Related Disorders Forum**

September 24, 2014 ♦ 8:30am – 2:00pm  
Holiday Inn ♦ Harrisburg

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- 8:30 – 9:00 am**                      **Registration (Lobby)**
- 9:00 – 9:15 am**                      **Welcoming Remarks (Dauphin Ballroom)**  
– Secretary of Aging Brian Duke  
– Message from Governor Tom Corbett
- 9:15 – 9:30 am**                      **Introduction of facilitators and discussion of the goals for the  
Breakout Sessions (Dauphin Ballroom)**
- 9:30 – 10:30 am**                      **Breakout Sessions:**
- Recommendation 1:**  
Awareness, knowledge, and sense of urgency about medical, social,  
and financial implications of ADRD  
(*Lancaster Room*)  
Facilitators – Michael Ellenbogen and Robert Marino
- Recommendation 2:**  
Collaboration to pursue financial opportunities and resource (*East  
Derry Room*)  
Facilitator – Kathy Jedrziwski, PhD
- Recommendation 3:**  
Promoting brain health and cognitive fitness  
(*Middle Paxton Room*)  
Facilitator – Brian Duke
- Recommendation 4:**  
Provide a comprehensive continuum of ethical care and support (*West  
Derry Room*)  
Facilitator – Kelly Carney, PhD, CMC

**Recommendation 5:**

Family and caregiver support  
(*Susquehanna Room*)  
Facilitator – Beth Herold

**Recommendation 6:**

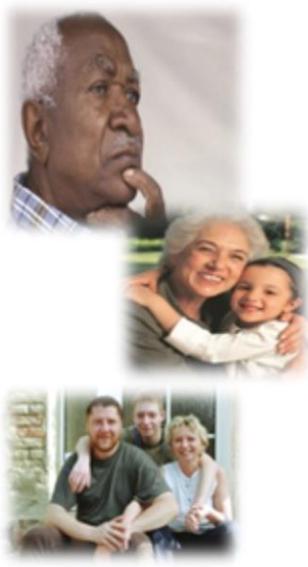
Build and retain a competent, knowledgeable, ethical and caring workforce  
(*Capital Ballroom East*)  
Facilitator – Heidi Owen

**Recommendation 7:**

Research, treatment, cure and preventive strategies  
(*Capital Ballroom West*)  
Facilitators – David Leader and Mickey Flynn

- 10:30 – 10:45 am**      **BREAK (*Ballroom Level and Lobby Level*)**
- 10:45 – 11:45 am**      **BREAKOUT SESSIONS (*continued*)**
- 12:00 – 12:10 pm**      **MAKING SENSE OF ALZHEIMER’S (*Dauphin Ballroom*)**  
– Barbara Overholser, Editor, [makingsenseofalzheimers.org](http://makingsenseofalzheimers.org)
- 12:10 – 12:45 pm**      **LUNCH (*Dauphin Ballroom*)**
- 12:45 – 1:45 pm**      **KEYNOTE SPEAKER (*Dauphin Ballroom*)**  
– Randi Chapman, Director, State Affairs for the Alzheimer’s Association
- 1:45 – 2:00 pm**      **CLOSING REMARKS (*Dauphin Ballroom*)**  
– Secretary of Aging Brian Duke

**Appendix B. Randi Chapman, Esq. – Keynote PowerPoint Presentation**



Pennsylvania State Plan for Alzheimer's  
Disease and Related Disorders Forum  
September 24, 2014 ♦ 8:30am – 2:00pm

Randi Chapman  
Alzheimer's Association  
Director, State Affairs

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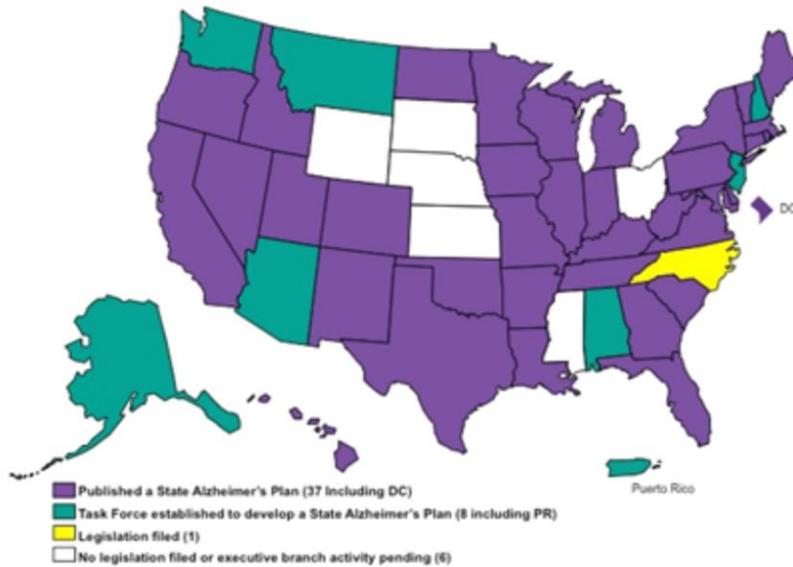
# So You've Got a State Plan...

## Now What?



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### State Government Alzheimer's Disease Plans



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## State Plan Implementation Infrastructure

- Organize Timeline to Achieve Goals
- Assign Responsibility for Plan Recommendations
- Annual Report to Legislative Committee (and others)
- Reconvene Task Force or
- Establish State Alzheimer's Advisory Council

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## PA State Plan Recommendations

- Raising awareness and knowledge about implications of ADRD
- Financial opportunities and resources
- Brain health promotion
- Continuum of care
- Family caregiver support
- Workforce development
- Research opportunities

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## State Implementation in Action: Colorado



### Colorado State Plan

- Published in 2010
- Legislation authorized formation of CO Alzheimer's Coordinating Council
- One of the best examples of using state plan to inform and shape state policy response to Alzheimer's epidemic

### PA Recommendation 1: Public Awareness

- 2 year public awareness campaign on early detection and *10 Warning Signs of Alzheimer's*; includes radio, online and TV outlets

### PA Recommendation 5: Support for Family Caregivers

- Alzheimer's Association working in partnership with AAAs promoting training materials for family caregivers

### PA Recommendation 6: Building competent, knowledgeable, caring workforce

- Create state certification in dementia care for facilities, agencies and individual licensed and monitored by the CO Department of Health and the Environment "Leaders in Dementia Care" certification program
  - mandatory, but strong incentive for facilities and agencies to participate



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## State Implementation in Action: Massachusetts



### Massachusetts State Plan

- Published in 2012
- Developed at request of Governor Deval Patrick by the MA Executive Office of Elder Affairs
- Partnership with the Alzheimer's Association, MA/NH Chapter and a statewide Advisory Committee

### PA Recommendation 1: Public Awareness

- Grant secured to expand Early Stage engagement and launch a public awareness campaign including paid and earned TV PSAs
  - Positive message on importance of getting help early, reducing stigma and accessing appropriate diagnosis, support and care

### PA Goal 1G: Improving Safety

- State aging office meeting with MA Ass'n of Chiefs of Police to discuss communication improvements, training and awareness
  - Pilot project includes data sharing

### PA Goal 1H: Protection from abuse and financial exploitation

- Webinar training for financial planners on fraud and abuse
  - Very well received—additional trainings needed

### PA Goal 4A: Assessment of needs/strengths along continuum of care

- Alzheimer's and Related Dementias Acute Care Advisory Committee.
  - strategy to address dementia-capable care in all acute care settings

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# State Implementation in Action: Minnesota



## Minnesota State Plan

- Published in 2011
- MN Board on Aging in response to legislature established Alzheimer's Disease Working Group
- Subgroup of ADWG committed to implementation established ACT on Alzheimer's

## PA Recommendation 1: Public Awareness

- [www.ACTonALZ.org](http://www.ACTonALZ.org)

## PA Goal 1F: Dementia Friendly Communities

- Community toolkit web-based guide to help communities assess dementia

## PA Goal 4C: Care Coordination

- Care Coordination in Health Care Settings Practice Tool

## PA Recommendation 5: Caregiver Support

- Economic modelling to predict cost savings of in-person caregiver support
- *After a Diagnosis*
  - Tips and resources for caregivers once diagnosis is made

## PA Recommendation 6: Workforce Development

- Dementia Curriculum
  - 10-module interdisciplinary curriculum for professional education programs

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HOME THE COLLABORATIVE • COMMUNITY TOOLS • ECONOMIC IMPACT • PROFESSIONALS • GETTING HELP • HEALTH EQUITY



## Is your community prepared?

**Take Action Now!**




**88,000 Minnesotans age 65+ live with Alzheimer's disease and the number is growing.**

Communities are taking action.

This site provides a toolkit and resources to guide communities in becoming dementia friendly, practice tools to assist professionals in identifying and managing the disease and an economic model of dementia intervention with projected cost savings.

By coming together to create supportive environments for everyone touched by this disease, Minnesota will be prepared for Alzheimer's.

### At a Glance

Preparing Minnesota Communities (brochure)

The work and passion of ACTing (video)

ACT on Alzheimer's is a volunteer driven, statewide collaboration preparing Minnesota for the impacts of Alzheimer's disease and related dementias.



## COMMUNITY TOOLS

[Home](#)

Find dementia friendly resources for all parts of the community illustrated by clicking on the clouds.

Download [two-page](#) and [four-page](#) brochures on preparing Minnesota communities.



Community by community, as awareness of Alzheimer's grows, we can take



## HOUSING AND RESIDENTIAL SETTINGS

[Home](#)

### Action Resources: Housing and Residential Settings

Older adult residential settings that serve and support people with dementia may have memory loss services available and they typically stress person-centered home safety and modifications in their settings.



#### Dementia-Friendly Residential Settings: Memory Loss Services (PDF, 06/16/14)

Steps to be aware, to find resources, and to maintain a dementia-friendly environment

### Home Safety and Modifications – Older Adults and Dementia Specific

**Safe at Home** Short video that offers caregivers of those with dementia simple, inexpensive options for making basic home modifications to help address problematic behavior when providing care at home.

**This Caring Home** Provides tips and tools to enhance home safety for persons with Alzheimer's and other types of dementia.

**Home Modifications** Home modifications are changes made to adapt living spaces to meet the needs of people with physical limitations so that they can continue to live independently and safely. This webpage helps you think through which modifications might be needed and how to begin.

**Home Safety for People with Alzheimer's Disease Booklet** for caregivers gives room-by-room suggestions for creating a safer space for people with Alzheimer's disease.

### Landlords – Older Adults and Dementia Specific

**Frequently Asked Questions** about reasonable accommodations for seniors.

**Landlords: The Critical Role of Dialogue Between Mentally Disabled Tenants and their Landlords in the Interactive Process** A legal perspective of a landlord's responsibility to accommodate tenants with dementia or other mental disability.

### Residential Settings – Dementia Specific

**Toolkit for Promoting Behavioral Health in Nursing Homes** Addresses non-pharmacological approaches to dementia care with an emphasis

# State Implementation in Action: Minnesota



## Minnesota State Plan

- Published in 2011
- MN Board on Aging in response to legislature established Alzheimer's Disease Working Group
- Subgroup of ADWG committed to implementation established ACT on Alzheimer's

## PA Recommendation 1: Public Awareness

- [www.ACTonALZ.org](http://www.ACTonALZ.org)

## PA Goal 1F: Dementia Friendly Communities

- Community toolkit web-based guide to help communities assess dementia preparedness

## PA Goal 4C: Care Coordination

- Care Coordination in Health Care Settings Practice Tool

## PA Recommendation 5: Caregiver Support

- Economic modeling to predict cost savings of in-person caregiver support
- *After a Diagnosis*
  - Tips and resources for caregivers once diagnosis is made

## PA Recommendation 6: Workforce Development

- Dementia Curriculum
  - 10-module interdisciplinary curriculum for university professional education programs



## COMMUNITIES ACT – DEMENTIA CAPABLE COMMUNITIES TOOLKIT

[Home](#) • [Community Tools](#)

### Is your community prepared for the impact of Alzheimer's disease?

You, your neighbors, businesses, faith communities, organizations – everyone across your community can take action to create a supportive environment for people with dementia and their families.

The ACT on Alzheimer's® Dementia Capable Communities Toolkit gives your community a process and tools needed to become dementia capable. The toolkit offers four clear steps and processes:



**Connect**  
1



**Assess**  
2



**Analyze**  
3



**ACT Together**  
4

1. **Connect** key community leaders and members to understand Alzheimer's disease and its implications for your community. Then, form an Action Team.
2. **Assess** current strengths and gaps in meeting the needs that result from the disease and related dementias, using a comprehensive community assessment tool.
3. **Analyze** your community needs and determine the issues stakeholders are motivated to act on; then set community goals.
4. **ACT Together** to establish implementation plans for your goals and identify ways to measure progress.

Click on the action steps above to watch a short video describing each phase. [You can download the complete Dementia Capable Communities Toolkit.](#)

#### What is a dementia capable community?

A **dementia capable community** is informed, safe and respectful of individuals with the disease, their families and caregivers and provides supportive options that foster quality of life. Every community can take action to become dementia capable. [Read more about dementia capable communities.](#)

**TOOLKIT OVERVIEW (PHASES 1-4)**



**Technical Assistance for Communities**

-  **Community Awareness of Dementia and ACTion Role**
-  **Caregiver Support Priority and Local Resources**

## State Implementation in Action: Minnesota



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### PA Recommendation 1: Public Awareness

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### PA Goal 1F: Dementia Friendly Communities

- Community toolkit web-based guide to help communities assess dementia preparedness

### PA Goal 4C: Care Coordination

- Care Coordination in Health Care Settings Practice Tool

### PA Recommendation 5: Caregiver Support

- Economic modeling to predict cost savings of in-person caregiver support
- *After a Diagnosis*
  - Tips and resources for caregivers once diagnosis is made

### PA Recommendation 6: Workforce Development

- Dementia Curriculum
  - 10-module interdisciplinary curriculum for university professional education programs

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## State Implementation in Action: Oregon

### Oregon State Plan

- Published in 2012
- One of the best examples of using state plan to inform and shape state policy response to Alzheimer's epidemic

### PA Recommendation 1: Public Awareness

- 3 year grant from ACL to State unit on aging for outreach and marketing, increased training for ADRC staff and development of Alzheimer's website
  - includes specific funding for outreach to Spanish-speaking residents
  - one stop shop website which will be promoted with awareness campaign

### PA Goal 1F: Dementia Friendly Communities

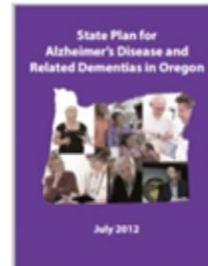
- Governor's task force on special needs transportation
- Gatekeeper Program expansion

### PA Goal 4F: Innovation in Service Systems

- Telemedicine program with VA physicians to reach patients in rural areas
  - Physician handles initial visit in person; follow-ups done remotely at local clinics/health centers
  - Program expanded into neighboring state (Idaho)

### PA Recommendation 5: Support for Family Caregivers

- Alzheimer's Association working in partnership with AAAs promoting training materials for family caregivers



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## State Implementation in Action

### FLORIDA

- Enhanced Special Needs Shelter Program
  - Registration program
  - Ensures that memory disorder clinics have access to registry and are including clients on registry

### NEW MEXICO

- Created and staffed Office of Alzheimer's/Dementia Care within NM Aging & Long-Term Services Department

### TEXAS

- TX Alzheimer's Research and Care Consortium
  - Collaboration among six of the state's leading medical research institutions to improve early diagnosis, treatment, and prevention of Alzheimer's disease
  - Focused research on impact of ADRD among Mexican communities
  - Over \$27 million in state funding

### VIRGINIA

- Created and funded Dementia Services Coordinator
- Significant success in expanding availability and access to dementia-capable Medicaid and other state-level services

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**CONTACT:**  
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### Appendix C. Attendee List with Contact Information

Last Name	First Name	Email	Organization
Arcurie, CHPN	Linda	larcurie@vnahospice.org	VNA Hospice and Home Health of Lackawanna County
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Barth	Ron	ron@leadingagepa.org	LeadingAge PA
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Burns, BS/SSC	Alexa	alburns@yorkcountypa.gov	Pleasant Acres Nursing & Rehabilitation Center
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Comarnitsky	Amy	acomarnits@pa.gov	Pennsylvania Department of Aging

Last Name	First Name	Email	Organization
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Cubit	Kathy	cubit@carie.org	Center for Advocacy for the Rights and Interests of the Elderly (CARIE)
D'Agostino	Franca Maria	fdagostino@pa.gov	Pennsylvania Insurance Department
Dauber	Jeffrey	jdauber@alz.org	Alzheimer's Association - Greater Pennsylvania Chapter
Day	Claire	cday@alz.org	Alzheimer's Association - Delaware Valley Chapter
De Obaldia	Anna Lisa	adeobaldia@hmc.psu.edu	Pennsylvania State University College of Medicine
DiLoreto	Art	arthur@p4a.org	Pennsylvania Association of Area Agencies on Aging
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Drescher	Jen	jdrescher@hcr-manorcare.com	HCR ManorCare Arden Courts of Susquehanna
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Eshelman	Diane	deshelman@pa.gov	Pennsylvania Department of Aging
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Getgen, RN	Susan	sgetgen@pa.gov	Pennsylvania Department of Aging
Gillespie	Kathy	kgillespie@ccaaa.net	Clearfield County Area Agency on Aging, Inc.
Gilmore	Paul	paul@olderpa.org	Pennsylvania Behavioral Health and Aging Coalition
Gingerich	David	dgingerich@pa.gov	Pennsylvania Department of Aging

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